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### Playing Voices: Building Knowledge About Caring Relationships in an Open Space

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#### Abstract

Patient involvement is grounded in the notion of the human being as an autonomous and speaking subject. However, this raises challenges when persons with speech limitations are invited to participate. Besides that, not every experience or meaning can be expressed in words easily. In this article, we learn about the potential of a new inclusive way of creating knowledge through Lego DUPLO blocks used in a study on caring relationships with clients with acquired brain injury (ABI) and their (in)formal caregivers. DUPLO offered a space for all involved to express their voice. People with ABI as well as (in)formal caregivers were challenged to move beyond verbal, cognitive, and normative expressions. Also, the unsayable aspects of care became visible and started reflections and encouraged to imagine caring relationships

among the participants. This approach is also relevant for (art) education, as it challenges traditional methods and disrupts epistemic injustice in research.

### **Introduction**

The involvement of patients in health care and health research is an emerging trend (Beresford, 2002; Barnes & Cotterell, 2011; Majid, 2018; Woelders, 2019). While experts usually decide about treatment options and research, people who receive care also deserve a say in decisions that affect their lives and wellbeing to attune care to their needs and lifeworlds. In addition to democratic and ethical arguments, the experiential knowledge of patients about their illness and the care they receive has been increasingly acknowledged as valuable. This knowledge is considered unique because it cannot be acquired without undergoing the experience (Dings & Tekin, 2022). It is assumed that this unique perspective can contribute to a better quality of care (Barnes, 2005; Schipper, 2011; Teunissen, 2014).

Various approaches involve patients in care and research (Greenhalgh et.al., 2019), but almost all of them are grounded in the notion of the human being as an autonomous and speaking subject. The underlying assumption of this approach is that people's perspectives and voices can be retrieved by listening to what they tell us about their lives and experiences. This may well be the case for people who receive care, who are still independent, relatively vital, and who can articulate themselves in spoken language. There are, however, also people with cognitive impairments, such as dementia, intellectual disabilities, or Acquired Brain Injury (ABI), who cannot express themselves verbally. Questions arise with regard to how to involve such people in research and to learn about their perspectives, what matters to them, and what their needs are. This is an urgent matter to be addressed, because to attune care well to their experiences and needs it is important that there are ways to involve also patients who cannot express themselves easily. Non-participation can lead to situations where decisions are made for them, without involving their perspectives on care, leading to "epistemic injustice" (Carel & Kidd, 2014; Fricker, 2007): a situation where the experiences of clients are not taken into account and their experiential knowledge in health care and health research is not valued.

As researchers working from a tradition of a participatory research approach, and more specifically, responsive evaluation, we have experienced the challenges that come with striving for the involvement of people who cannot express themselves easily (Abma, 2006; Abma et al., 2009; Abma & Widdershoven, 2014; Abma et al., 2017; Visse et al., 2012, 2014). To ensure that all people involved can share their experiences, we explicitly aim to include the perspectives of all people, with special attention to those whose voices are not easily heard. Involvement, dialogue, and mutual learning are central to a heightened personal and mutual understanding among many participants. In health care and health research, this

means involving people who receive care (patients or clients), their relatives, health care professionals, and others, depending on the practice or issue under scrutiny.

People living with conditions that impair cognition due to brain disorders, such as Alzheimer's disease and related dementias or language, as well as aphasia are significantly underrepresented in health research (Groot et al., 2023). Other scholars have also raised this pressing issue, and there has been a call to action to explore ways this underrepresented group may be involved (Backhouse et al., 2016, p. 337). Others have raised similar concerns about the “misfit” of verbal methods (Webb et al., 2020) and recommend the use of non-verbal and creative methods.

We found several examples wherein researchers searched for other ways to gain understanding of the experiences of non-verbal clients. Besides auto-ethnography (Bos & Abma, 2021), we found creative and arts-based methods (Phillipson & Hammond, 2018) such as participatory photography (Dooley et al., 2021), bricolage (Baur & Abma, 2012; Woelders, et al., 2018), and poetry (Synnes et al., 2021). Arts-based research not only aims to offer a space for expression for those with speech problems but is grounded in the epistemological notion that besides factual knowledge (ontic realm) there is knowledge that cannot be expressed in words, the so-called “unsayable” (Visse et al., 2019, p.1) which gives us insights into other layers of experienced reality, including emotions and intuitions (ontological realm) and perhaps even the un-knowing (Visse et al., 2019).

In one of our research projects, the urge to rethink the voice of people who cannot express themselves verbally came to the fore in our daily practice. It was a project in the context of health care involving people with an Acquired Brain Injury (ABI). People with ABI have brain injuries that are not congenital, do not occur as part of the developmental process, have a rapid onset related to sudden trauma or disease process and are non-progressive in that degeneration is not expected (McDonald & Shumway, 2002). Hearing their voices and getting to know their experiences was complicated due to the communication problems present with the majority of individuals with ABI, so-called Cognitive Communication Disorder (Togher et al., 2014). Cognitive communication impairments occur due to underlying problems with cognitive skills such as attention, memory, organization, reasoning, social cognition or executive functions (McDonald & Shumway, 2002). The problems come primarily from non-linguistic cognitive impairments rather than from language impairments as is the case in aphasia (McDonald et al., 2014).

In this research project, we investigated the experiences of people with ABI and the attunement of care between them, and their informal and formal caregivers. Our questions included: What are their perspectives on care? How do they experience the attuning of care in their mutual relationships? What are the moral challenges surrounding the attunement of care?

Before we present our view on care below, we experienced involving the voices of all stakeholders was challenging and had significant limitations due to the above-described communication difficulties of people with ABI. Traditional methods (often verbally orientated) were not sufficient, so in our aim for equal opportunities for all involved to express themselves and share their perspectives, we wanted to search for other ways to foster equal involvement (Hendrikx et al., 2022).

Another challenge we came across in our daily research practice was how the involved people (people with ABI, their informal caregivers and the professionals) expressed the experienced attunement of care in relationship to each other. The moral issues concerning the division of care responsibilities were a part of all themes. We consider care to be a relational phenomenon and derive from an ethics of care perspective. Care is not only about the person who needs or receives care, but is something that happens in a certain context and in relation to the people who give care (Tronto, 1993). Expressing relational and moral aspects defied articulation by words. From the perspective of care ethics, care is more than ‘caring for’ someone or literally following rules and principles like the patients’ autonomy. Good care also entails *caring about* someone and feeling morally responsible for the person. Care is a reciprocal practice and requires intersubjective agreement of both the patient and caregiver(s). These emotional and moral dimensions infuse the caring relationship and are difficult to express in words (Tronto, 1993, 2013; Visse & Abma, 2019; Zembylas et al., 2014).

These moral-relational dimensions of care are even more challenging in a context wherein responsibilities endowed to caregivers are changing. Societal developments including post-individualism, emancipation, and ageing populations have led to transitions in healthcare. In many Western countries, professional care activities are reduced, and family members are expected to fill the gaps. For example, in Dutch healthcare policies, the concept of “customary care” (in Dutch: ‘gebruikelijke zorg’) has been introduced, and is defined as the daily, normal care that can be expected from social ties (CIZ, 2014). Family members (including significant others) are now important stakeholders, but they have for a long time been neglected and undervalued in healthcare (Lindeman, 2007). It is therefore not clear what the moral expectations (norms) and the caring responsibilities of families are (Grootegoed et al., 2015). In our research project, we analyzed care responsibilities assigned to family members of people living with ABI. ABI is a complex disease difficult to deal with for families and professionals. It causes diverse and often hidden disabilities such as hypersensitivity to stimuli, reduced self-understanding, an inability to indicate boundaries, varying levels of energy, concentration difficulties, and often problems with, as mentioned above, communication. Therefore, we aimed to develop a new way of working that: a) gave the people with ABI an equal opportunity to express themselves and let their voices be heard; and b) provided an opportunity to learn about relational aspects between the formal caregivers,

family, and clients (from now on called a ‘triad’), from all perspectives.

The purpose of this article is to describe our experiences re-searching for new ways of involving people living with ABI and their caregivers in research. We used colorful Lego DUPLO blocks to visualize the voices and experiences of people with ABI and other participants. Below we sketch the context and research setting, the development of our way of working, and how this new approach was used in our study. Then, we present our learning experiences and relate these to our expectations of hearing all involved. Finally, we reflect on these learned lessons, and the implications for those involved in care, art, and education.

### **Context and Research Setting**

The research project followed a responsive evaluation approach and focused on the unique experiences and narratives of the persons belonging to various stakeholder groups, giving each a voice in a dialogue over care responsibilities (Abma, 2006; Abma et al., 2009; Abma & Widdershoven, 2014; Abma et al., 2017; Visse et al., 2012, 2014). We distinguished three stakeholder groups: people with ABI (from now on: clients<sup>1</sup>), informal caregivers and professional caregivers. Taking into account the dynamics in the triad client-family-professional, we studied seven triads to gain an in-depth understanding of the assignment of moral responsibilities within the triad (Walker, 2007; Landeweer et al., 2011). In each triad a client with ABI (C), an informal caregiver (I), and a professional caregiver (P) were involved. We approached each triad as a particular case, understood from multiple stakeholder perspectives (Abma & Stake, 2014). In total, we completed 20 interviews.

The VU University Medical Center Medical Ethics Review Committee reviewed the study and determined the Medical Research Involving Human Subjects Act (*Wet op Medisch Onderzoek, WMO*) did not apply to this project: *Niet-WMO-advies METc verklaring VUmc* (2016, p. 157). All participants provided written informed consent.

### **Beyond the Verbal: Exploring New Ways to Make Voices and Experiences Visible**

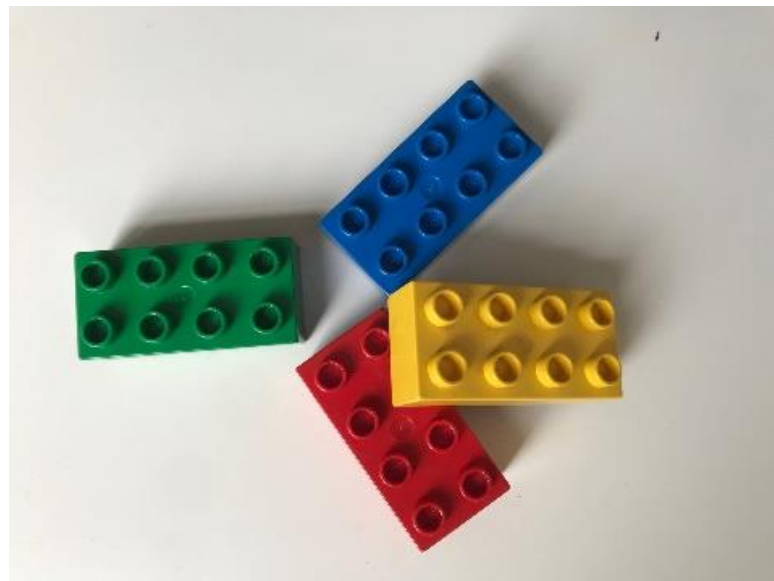
To enrich traditional methods of in-depth interviews, we aimed to find expressions beyond the verbal and searched for how to visualize experiences. Because of the ABI characteristics, such as low cognitive capacity, varying energy and concentration restrictions, the interview was

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<sup>1</sup> For the sake of readability, we use the word client in this article. We do realize that making choices for this term for people who receive care can bring along associations that do not fit the person or context. In our daily research practice, we prefer to let people choose how they want to identify themselves. In this article we use the term client because this is common in the care context of this research setting. We also use person/people with ABI, because this is the way the involved people defined themselves.

enriched by a tool that challenged the person to share their experiences accordingly, rather than verbally. In addition to being visual, we wanted the tool to be active, creative, and challenging, offering space to play. To strive for equity in our approach we used the LEGO DUPLO blocks for all involved stakeholders (the person with ABI, informal caregiver, and professional).

DUPLO blocks have simple forms and clear colors that are easy to handle. The simplicity and recognizability were considered important because clients with ABI experience enhanced sensitivity to stimuli. We believed the material should not require extra energy from people with ABI. Moreover, we reasoned that DUPLO is associated with the feeling of playing and creative constructing. Different colored blocks can represent distinct perspectives in the triad and visualize relationships and their qualities. We hoped the method would invite lightness and ‘breathing space’ to the tense subject of caring relationships and responsibilities. To facilitate this lightness, we created space for imagination. First, people participated in interviews followed by an invitation to build experienced situations of care and care responsibilities in the triad. Additionally, respondents built their ideal care situation. This resulted in constructions representing their present experiences as well as their ‘care imaginaries’ (Visse & Abma, 2019).



*Figure 1.* The four colours and building blocks.

We piloted and chose four colours representing various stakeholders (see Figure 1):

Yellow (one): representing the client (C)

Blue (3 big, 2 small): the informal caregiver (I)

Red (3 big, 2 small): the professional caregiver (P).

Green (1 big, 2 small): other organisations (O) such as municipalities/institutions.

We piloted the approach, and to reduce stimuli overload decided to use green blocks only when participants need 'others'. Participants needed time to build and create constructions. The pilot also resulted in an instruction form used by the research team to consistently present the assignment to respondents.

The in-depth interview consisted of two parts: a verbal part (max 60 minutes), based on a topic list, and a 'building' part (max 30 minutes). To create trust and safety, we started with the verbal interview. For the 'building part', every participant was free to build their construction, reflect, and imagine. Depending on their capacities and energy levels, the duration of the oral part versus the building part was flexible. Before starting, we informed each participant about the interview's structure, and told them they could stop the interview at any point.

After the verbal part of the interview, we placed 11 blocks in three colors on the table. We explained what each color represented and invited participants to build their experiences of attuning care to the person with ABI. The researcher observed and did not ask questions. The participant was given unlimited time to construct and re-construct. In building constructions, it was made clear that there was no wrong, and there was no right. Each voice was given space and potentially empowered through the free space of play. When the participant indicated to have completed the building process, they could explain their work. The researcher could question to clarify or to deepen the understanding of the situation. In addition, participants built visualizations of their ideal care situation (care imaginary). Photos were taken of both DUPLO constructions in order to analyze these together with the transcripts of the interviews.

The interview transcripts, field notes, and images of the DUPLO constructions were analyzed using a phenomenological and interpretative approach (Smith et al., 2009). This involved reading and rereading the interview transcripts and field notes. Initial notes and reflections were discussed and led to a set of emerging themes. Connections across themes and cases crystalized through discussions within the research team. In this article, we continue by focusing on the in-depth interviews. In addition to the material gathered, this team of authors organized a series of evaluations and reflections specifically focused on the DUPLO method through a series of online group conversations. These took place over a longer period of time (2020-2022) after completion of the study. The topic of our conversation was whether and how the method fostered the voice of the client and their involvement in the research. In our conversations, we used the study's data, but with a specific lens on the method and its

potential for involving clients with limited speech.

The following section presents our experiences with the visualization method and delves into the learned lessons.

### Findings: Experiences and Learned Lessons

#### *Experiences of the Participants in General*

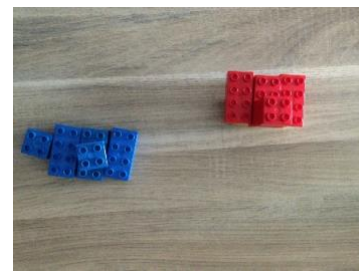
Every participant reacted positively to the invitation to build their care situation with DUPLO blocks. Building caring relationships, being creative and active, provided them with new energy and lightness after sharing—mostly—tough stories in interviews. The invitation to construct caring relations created an atmosphere for new experiences to emerge. For example, an informal caregiver said: “*I am not so talented with creativity*“, but she dove into the task with energy, bringing her immense joy and being proud. Feelings of surprise and pride were displayed across a broad range of situations and among all participants. After sharing their stories with us through interviews, the DUPLO method evoked a feeling of play with all stakeholders. Expressing one’s voice in another, unexpected and ‘free’ way gave participants the freedom to choose their direction. The result was a diversity in constructions, as we show below (Figure 2)<sup>2</sup>.



2a



2b



2c

Figure 2: Diversity of constructions by participants.

Below we delve deeper into the experiences and lessons learned through three themes:

1. Building caring relationships with DUPLO, striving for equivalent input; beyond verballity

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<sup>2</sup> Some photos of the building structures have been rebuilt as a copy from the original creation and photographed again for the sake of image quality and communication value.



2. Building caring relationships with DUPLO, gaining insight into mutual relations and their complexity
3. Building caring relationships with DUPLO to stimulate reflection

***Theme 1: Building Caring Relationships with DUPLO to Strive for Equivalent Input; Beyond Verbality***

One of the reasons to develop our DUPLO approach was to offer a space for the less cognitive and verbal participants to express themselves, creating space for their ‘voices’ by building blocks. Most persons with ABI felt invited to do so. In some situations, participants hesitated, and the encouragements by the researcher such as “it is always good” were helpful. Clients dared to think about their actual and desirable situations and took the lead. They ‘named and valued’ the blocks. For instance, a man (C) first labeled the blue block his informal caregiver, but later relabeled this block as the family-system, and after that, he included a neighbor. During building, he named the blue blocks “the social system”, necessary for “the emotional care.”

Building the desirable situation invited clients to reflect on their ideals. They began to ponder: Which change will I make, and what do I want? Some participants were challenged to dream. Sometimes this resulted in an entirely new construction. Others made little but meaningful moves, such as the young man (C) who put for the desirable situation only one yellow block (himself) on the other side of the caregivers and said clearly:

*“This is what I want. I try to shut myself off. The most desirable situation is that they are all gone. I have to move forward... the caregivers in the back.”* (see Figure 3)



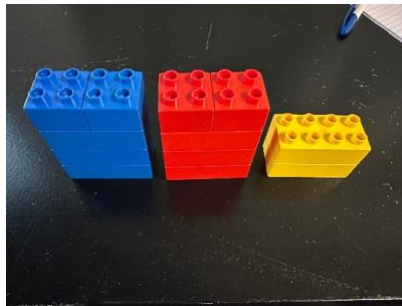
3a



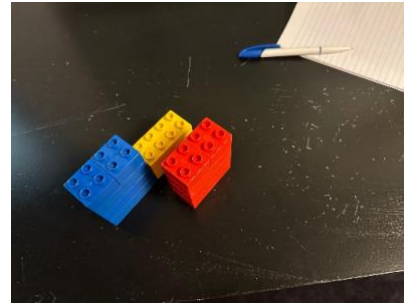
3b

*Figure 3. Client: ‘This is what I want.’*

In Figure 4, a woman with aphasia (C, in yellow) couldn't share her experiences easily in a verbal way. She built her actual situation, in which she visualized her experience with her informal caregiver being far from her (4a, informal caregiver in blue). She then visualized her needs in the ideal situation by showing her place next to the blue block and next to the professional caregiver in red (Figure 4b). She did not articulate this verbally and didn't share any words, but her voice was 'heard' through her visual construction.



4a



4b

*Figure 4.* Client (yellow): Getting closer to the informal caregiver (in blue).  
(In this particular situation, the interviewer used two yellow blocks for C)

The examples illustrate how clients exerted autonomy and expressed their voice by using the blocks. This is meaningful because instead of being dependent, as is often the case in care situations for people with ABI, clients determined themselves how to use the blocks.

We learned the DUPLO method not only created a space to hear the voices of the less verbal participants but also increased equality among participants. Take, for instance, an interview with a professional caregiver who we considered was verbally well-articulated. While working with the blocks, she hesitated to place the blocks in a certain way. She increased the space between yellow, blue, and red (C and I/P) and explained: *“Because she [C]... it is just my feeling... she is on her own.”* It was clearly a different voice – not the confident voice of an expert who knows what to do and we heard during the oral interview, but a voice full of doubt and uncertainty that spoke. The DUPLO method pulled her away from her familiar verbal approach and created space for her to connect with emotions and feelings and to express them.

Another example is a female informal caregiver (I) who shared a familiar story she was used to telling. In the oral interview, she talked about her major care responsibility in care for her relative. In the DUPLO construction, however, she barely created space for herself. In the construction, her role was less involved than in her verbal account and professional caregivers

took center stage. This revealed a discrepancy between what she said (which may have been a socially desirable answer) and what she experienced and built. We found other occasions where emotions were uncensored, as in the next situation of a man (I), who built his ideal situation. He built very quickly, and while looking at it, he placed more and more blocks, resolute and with a lot of power, stipulating: *“It should be one chunk, it should be one amalgamation.”* The way he built was accompanied by emotion, expressed anger, feelings of powerlessness and an emotional cry about the lack of collaboration between caregivers (see Figure 5).



*Figure 5. An emotional outcry by an informal caregiver: “It should be one chunk, it should be one amalgamation.”*

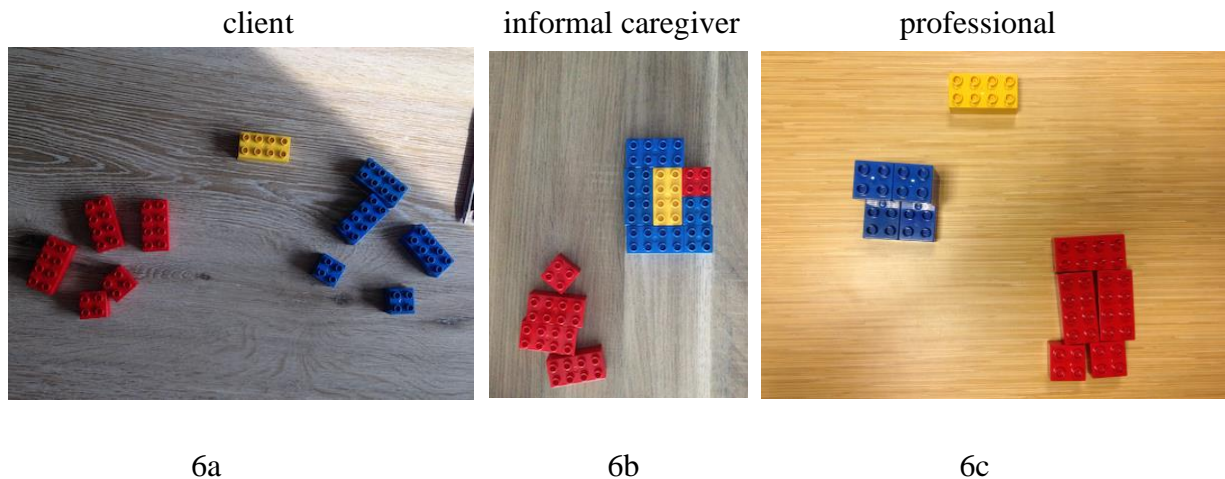
Building with DUPLO blocks offered space for another way of thinking, beyond verbality, and beyond socially desirable ideas or expectations. In that sense, DUPLO was not a new manner that replaced, stressed or ‘translated’ verbal narratives in color and form. Instead, it offered an opportunity to express another voice than the verbal, cognitive one. It gave space for the ‘unsayable’ (Visse et al., 2019), to express feelings and matters not easily put in words, especially about caring relationships. Saying “there must be more distance” seemed, for example, more difficult than visualizing the distance through DUPLO blocks.

We conclude that the DUPLO assignment offered a space for persons with ABI with limited speech to express themselves and exert autonomy. It created equivalent input, not only because clients were given visualized voices to bring perspectives to the fore, but also because

all participants, including the informal caregivers and professional caregivers, were challenged to go beyond verbal, cognitive, and normative expressions.

***Theme 2: Building Caring Relationship with DUPLO to Gain Insight into Mutual Relations and Their Complexities.***

We also intended to develop in-depth insights into complex mutual caring relations from the perspectives of all stakeholders within the triad. The DUPLO constructions clearly visualized how stakeholders within the same triad showed their perspective on the relationships. Below (Figure 6) we see one triad, visualized from three perspectives.



*Figure 6. Multiple perspectives on the same triad (Care constellation of client and caregivers).*

In the oral interviews, the complexities of these relationships were mentioned, but were not elaborated. With the simple forms like DUPLO blocks and their bright colors, the mutual relations and the complexities of caring relationships were translated through 'easy accessible ways', as demonstrated in the following visual constructions. Figure 7 shows the perspective of an informal caregiver on the caring relations (see Figure 7).

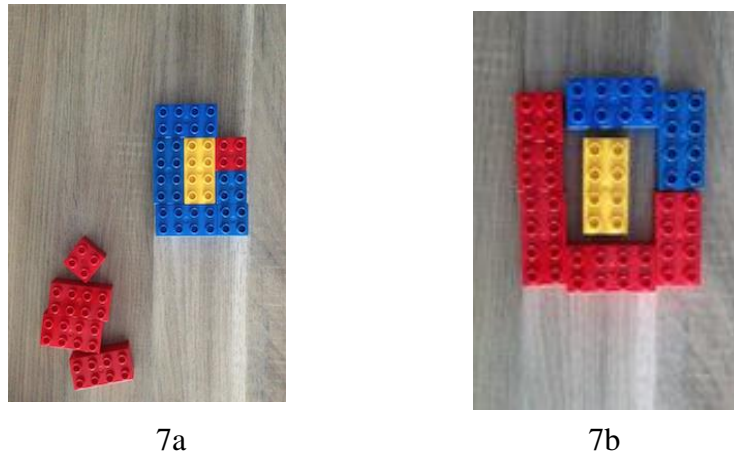


Figure 7. The perspectives of an informal caregiver.

In the actual experienced situation (7a), we see the perspective of the I (blue) which C (yellow) is fully enclosed, there is literally no space between them. It is an image of a suffocating situation. C is completely wedged. Some professional care (red) at one side is connected and most professional care is at distance. Her construction of the desirable situation (7b) differs clearly from the actual situation. First, we see space between the client and the caregivers. The number of blocks representing informal care is less than formal care, more in balance, and they are fully connected to each other. While she tried to explain this in the interview, her perspective came to the fore and was better articulated the DUPLO construction.

Building with DUPLO offered a way for participants to investigate their positions in relation to others. The constructions arose with attention to the positions of each involved, as highlighted by a person with ABI looking for their position, choosing placements of blocks in relation to caregivers. A small change in the placing of the yellow block – representing their position – took much attention and consideration. Images clearly visualized the meaningful changes in relationships with others in the care situation (see Figure 8). This client talked to himself during the construction and said:

*“Maybe it is strange to put myself in the center. I have to deal as much with the informal caregiver as the professional. Both are important, they are equal. Maybe on another area, but one is not more important than the other...but it feels strange to put myself in the middle... as if it were all about me, but of course that is not the case. Let me put myself as a connector instead of the center [he slides the yellow block a little but aside]. Of course, I am, but I have to deal with both. When they have to do with each other, the most convenient way is doing it through me.”*



8a



8b

Figure 8. Carefully choosing one's position in relation to others.

We learned that building the caring relationship with DUPLO shows every voice is needed to understand complex care situations. The informal caregiver is, for example, not only a proxy for the voice of the person with ABI, but also offers an additional perspective and voice.

The various DUPLO constructions were not only insightful for the researchers, but also heightened the participants' personal understanding of themselves. By building constructions of caring relations, each participant gained insights into their own basic assumptions about their own role, as we saw with a person with ABI building the desirable situation. She (C) put the I next to P, because, as she said, they have to take care of each other. '*The red ones must have the same distance to both*', indicating that she wanted also to take care of both. Building the actual and the desirable situation deepened the meaning of the mutuality of the relations. It invited participants, for example, to express their own perspectives on what collaboration means to them.

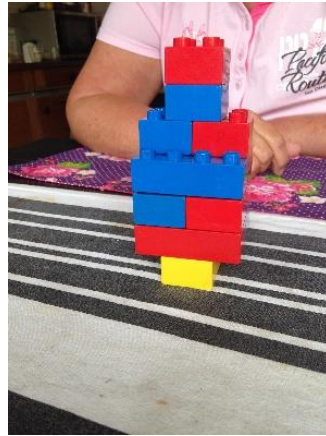
A woman (C) expressed her voice by building how she experienced her caring relations (see Figure 9).



9a



9b



9c



9d

Figure 9. Heightened personal understanding in the process of building.

After her first construct (9a), she took more red and blue blocks (9b, red presenting the formal and blue visualizing the informal caregivers). She ruminated and said:

*“This one, [pointing to the overhanging blue block] is my informal caregiver, he is trying, but....[silence] he isn’t. The rest [pointing to the blue ones aside] are laying here” ...They are apart from her, she felt ignored, family and friends said :”we didn’t know...we didn’t see it .. This [pointing to the red blocks] is a....the professional side. That slides away occasionally. It is shaky”.*

Building the desirable situation, she took as many red as blue blocks and made a balanced, tall structure on top of the yellow one, built entirely on it (9c). This assignment stimulated her imagination. In her words:

*“The red and the blue ones should be equivalent and really in the middle, really in the middle is the yellow one... Balance will be probably an utopia.”*

Moments later she put the green blocks in between one (9d)

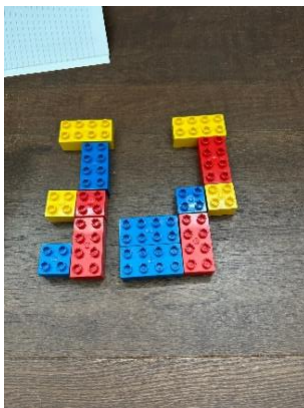
*“We will have to do it with all of us...[pointing to the green ones] the non-official will also have to participate equally.”*

We learned building caring relationships with DUPLO is more than representing complex care situations through materiality and imagination. It offers researchers another picture of the multiple perspectives on the caring triad. In our study, to participants, the process of building provided a space to enhance personal understandings of their positions and individual voices, as well as relational voices. It stimulated participants to investigate positions in the triad, spurring their imagination, which we will explore in-depth next.

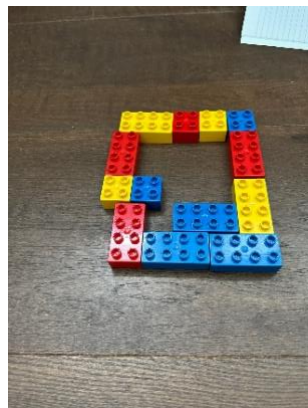
### ***Theme 3: Building a Caring Relationship with DUPLO to Stimulate Reflection and Learning***

As we have seen, building caring relationships with DUPLO gave participants the opportunity to interpret their situations, and to imagine and develop (different) perspectives. The building process itself, as well as the DUPLO imagery, invited participants to reflect on relationships. Reflection and learning were not typically verbally expressed, but also while moving blocks, accompanied by talk thinking, outward inner-dialogues, and sharing brief ruminations. We demonstrated this in the examples described above.

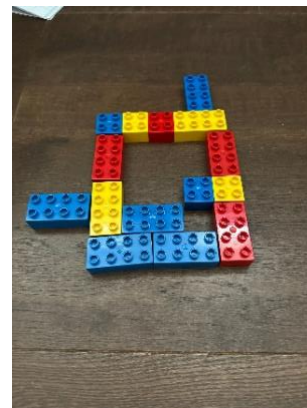
DUPLO invited participants to interpret and make meaning of complex relations and care situations, and to learn about the caring triad. Often, it resulted in a process of building and re-building, literally making sense. Sometimes oral narratives accompanied the building, giving us insight in the process of searching for meaning. For example, in the following situation, where a professional caregiver built and rebuilt her actual situation (see Figure 10).



10a



10b



10c

*Figure 10.* A learning process of a professional re-building the triad.  
(In this case, there are more yellow and blue blocks for the client).



The inner-dialogue of the professional building and re-building the situation:

*“On the right is the day, on the left is the evening”* (10a). *“She [C] will, but she always hangs out a bit”*... *“In fact I will give her [C] more blocks, it is about her”* [the researcher supported the professional in this case in having more yellow client-blocks].

*“Actually I should have built around her.”* She took the blocks away to build another construct (10b) *“actually I will create a round shape, then the circle is complete’*... *“we [P] do a bit of care, but actually she [C] determines and he [I] also. He is very dominant in the whole care event actually, that’s why I give him more blocks...we [P] are intermediaries”*.

She moved blocks and said: *“even though it is about her, we are all concerned about her... Even if she gets more voice about her care...in the situation it isn’t possible... It is a married couple after all.... he is actually connected to everything.”* (10c)

The image of the construct offered the professional caregiver an opportunity to look at it from a distance, entering an inner dialogue.

In another instance, an informal caregiver built his construction while reflecting on the situation he built (see Figure 11). Looking at the construction, he hesitated and said; *“hmmmm....I think I am too close to C... sometimes too close...”*

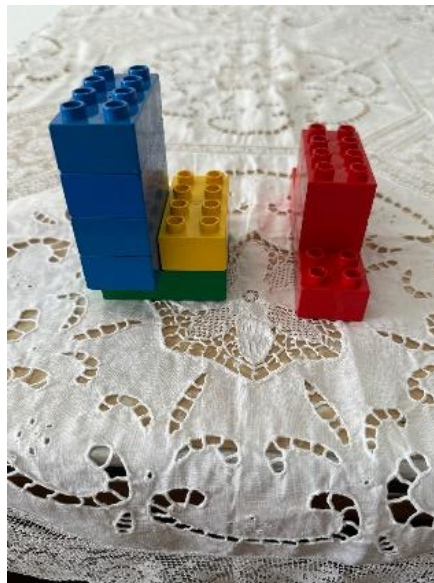


Figure 11. Informal caregiver reflecting: ‘Too close?’

The visualized positions triggered the participant: *Is this really how it is for me?* Building constructions resonated with their feelings more than with cognitive and normative dimensions ('this is the way it has to be'). During construction, the process of thinking and feeling is ongoing, offering space for doubt, letting go, and acknowledgment of not knowing the situation, like in the next example. A professional is building the ideal situation. She puts the I and the P in distance of the C, "because", she said: "I grant him this" (see Figure 12). Then, she looks on it and reflects: "Is this realistic?"



Figure 12. A professional caregiver reflecting: 'Is this realistic?'

We learned the DUPLO method offers more than an equal opportunity to all stakeholders giving their voice and gaining insights into relationships of care. It also offers rich insights in the concept of 'voice' related to 'patient involvement' in care, research and potentially education. We will discuss this in the next part.

## Discussion

This article provides insight into our experiences and learned lessons while using DUPLO as a new way of re-searching and visualizing voices of those who are less verbal to foster their involvement in care and research. We wanted all involved to have equal opportunities to express themselves and to have the possibility to share perspectives around care and care responsibilities in the triad. This moral horizon and striving for epistemic justice are important notions in participatory research approaches in contexts of care (Abma, 2020; Woelders, 2020). Additionally, we wanted to create space for the expression of relational complexities of care situations, including "unsayable" dimensions (Visse et al., 2019).

The findings show DUPLO blocks offer space for all involved to bring perspectives to the fore, not only people with ABI. It enriches the possibilities for informal caregivers and professional caregivers to give meaning to their experiences around the attunement of care. It helps them to construct and re-search their stories. It enabled all involved in the triad to make sense and interpret their own situations, and to ask new questions.

We learned that DUPLO did not only ‘fill in the verbal gap’, but created space for free play, beyond norms and expectations, thereby stimulating reflection and learning among all involved. The DUPLO material appealed to play, also because of the familiarity and manageability of the blocks. Playfulness means openness to explore and interpret a situation and its meaning, including the ambiguity, uncertainties, and surprises that may emerge in that process. This idea of play is grounded in the philosophy of Gadamer (1960), who compared the act of hermeneutic understanding and interpretation with play. Like in play, the process of interpretation is not dependent on the intentions or consciousness of those interpreting a situation. It is the playing that captures the players in a process (of interpretation) offering them new horizons because a wider band of consciousness than cognition and language resonate in the process. This appeals to the unsayable dimensions of the care reality (Visse, et al., 2019).

While our new way of working was developed to involve clients with speech limitations, we learned that it pulled cognitive and verbally skilled participants away from the familiar cognitive verbal and normative levels of responding. As a result, each and every participant became more aware of their voice and came to think for and about themselves. It stimulated all to become a ‘subject’ in the process of knowledge production instead of being an ‘object of research.’ It put researchers in the position not to *give* voice, which is an act of hierarchic power and reproducing asymmetry, but to create and facilitate a space for all voices, and to include them in the process of meaning-making.

This links up with the view that the researcher as expert is not the one who investigates an object, but it is the participants who are researchers themselves (Abma et al., 2019). As Walker (1991) mentioned, “research is re-search” and means to re-look (p. 41). With the invitation to use DUPLO blocks to visualize the caring relations within a triad each participant built, looked, re-looked and re-built new constructions, giving a sense of what he/she experienced. They investigated their own situations and sometimes arrived at new understandings. Therefore, not only is the end-result is important, but it is in fact the process of building that invites participants to reflect, learn and generate new insights. Therefore “hearing and giving voice” is not enough in patient involvement, it is the awareness of one’s own voice in relation to others that is an essential part of involving voices and hermeneutic justice (Fricker, 2007).

During the construction, a process of thinking and feeling was happening that offered space for doubt, letting go, and acknowledging the indeterminate, the not knowing. This applied well to the client, the informal caregiver, as well as to the professional caregivers, who were not used to doubt or to be ignorant. From here a process of signification started. This self-reflection generated another kind of knowledge: embodied or pathic knowledge (Van Manen & Li, 2002). The term pathic is derived from pathos, meaning "suffering and also passion" (Van Manen & Li, 2002, p. 220). Pathic knowledge refers to knowledge and understanding that are not cognitive, intellectual, rational, or technical, but relational, situational, physical, and action-oriented. This is the understanding achieved by putting yourself in the shoes of another (empathy) and by feeling what the other is feeling. Developing different forms of knowledge will enrich understanding.

To foster this process of interpretation and this kind of knowing requires a specific *ethos* of the researcher. This includes a kind of attention of the researcher, being there with the participant, around a table, together around the construction. Gustaaf Bos (Bos & Abma, 2021) describes this in his work with people with intellectual disabilities as follows: how he had to leave his comfort zone and "verbal weaponry" (p. 1720) to come closer to the world of those he could not speak with. This required an "attentive passive" (p. 1721) attitude, and a much more careful embodied approach wherein he had to listen and make sense of his own embodied experiences as well as those of the people he was working with. This is also the case for the DUPLO construction: the researcher shares control with the participant. The researcher is present with attention creating the right space wherein new understandings can develop. This clearly goes beyond the ontic realm of factual description; here we enter the ontological realm where all are involved to re-search the caring relationships (Visse et al., 2019).

In this article, we investigated the different voices of *one* triad. The duty of confidentiality, not sharing the stories with each other, was important for the participant to feel free to tell their stories. This generated in some cases a lot of tension. Participants entrusted us with stories that the others in the triad did not know. We sometimes felt frustrated and 'mangled' by hearing the perspectives of the other participants, without being able to respond. It required balancing 'knowing' and 'openness'. We, therefore, stress researchers must have the possibility to share their frustration and encountered problems with others in their teams.

As stipulated, the 'space to play' was essential to realizing hermeneutic justice. This brought unanticipated methodological challenges. The freedom of building one's own care situation with DUPLO blocks resulted in multiple different 'building constructions.' This made it difficult to interpret the situation. Not only the visual image was important, but the entire

process, and the way of building, including the inner-dialogues, accompanied with words during and/or afterwards were equally important for understanding. For the researcher, it was important to take all input into account, including the pictures, transcriptions and field notes. A recommendation is to make a video of the dynamics of the building process, instead of taking a static picture of the building construction. In a video, you could see the way people build, their tempo, their hesitations, the changes they make, and the verbal expressions that come along with building.

Traditionally researchers as experts are working in the ontic realm generating factual knowledge using methods for the sake of objectivity and generalizability. Creative and arts-based methods are unusual within this tradition. It was Plato who declared that the arts were merely a bad interpretation of reality. The arts were therefore not to be taken seriously. Positivistic researchers still follow this Platonian idea. However, great thinkers such as Husserl explained that the arts do not stand below science, but that they provide another way to understand reality. Science and the arts were complementary according to phenomenologists. We follow this latter line of thinking but working with creative ‘methods’ is not always easy to explain to more traditional researchers. We do not even think of it as another ‘method’ but rather as another epistemology, entering another realm of knowing.

A related point of attention is the member check to validate interpretations. To avoid another injustice, we had to think about how to communicate the member check to participants who have trouble with written texts. In our project, we offered participants a choice (written by post, by email or oral by telephone). They chose a written report, maybe because it is the most simple and recognizable form. Yet, we have to be critical in determining whether the participants have the capabilities and energy to read the material and have words to react to it. Therefore, we recommend investigating other ways of doing member checks in this context.

The DUPLO method can be used in a research setting, but it might also be a vehicle to improve everyday practices of care, as well as educational spaces, such as nursing programs, medical schools, social work programs, and even art education. The method can provide insight into all situations where people relate to each other and try to attune. This is not limited to care contexts, but can also be relevant for the practice of (art) education. It can help to understand the relational interwovenness of people and can stimulate self-reflection and inner dialogue, stimulating one’s own re-search.

Our study contributes to the increasing interest in care aesthetics (Thompson, 2022). And even though DUPLO is not art, our study confirms the significance of integrating non-verbal modalities and aesthetic approaches to contribute to improving insights of all people involved in the context of care and art education (Kooshab et al., 2023).

DUPLO potentially offers a starting point for an open dialogue between professionals, clients, and informal caregivers, but this would need further investigation. The method presented is not a fully structured method, it requires a special attitude of the researcher to prevent an instrumental use of it. Also, to further develop this method, we need to gather more extensive insights into experiences of applying the method in research, care, and education.

### Conclusion

The DUPLO method offered possibilities to give voice to less verbally equipped participants. Its use interrupts the epistemic injustice that exists when we stick to our traditional methods that exclude clients who have limited speech. This method ultimately provided significant insights. Even the verbally equipped participants developed a voice of self-direction, a voice beyond the rational and normative, a voice of imagination, in which feelings and doubts and deeper awareness flourished. Embodied and pathic forms of knowing came to the fore when building DUPLO constructions that made visual the care situation in a triad, creating images of the current situation as well as imagining what these caring relationships might ideally look like. This implies that 'patient involvement' is not only 'hearing the voice of the client' to understand their needs. To enrich 'patient involvement', we have to see the voice of clients as being relational, expressed in words and beyond words. Moreover, not only the voice of the client is needed, but also the voices of all stakeholders in the care situation, and these should not be considered as proxies or additional voices to the client, but as their own voices with their own perspectives. The DUPLO creates a space between playing and understanding, to develop insight in one's own voice, embedded in mutual caring relations. In the colorful interspace, new voices can breathe, creating a space for new meanings.

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